

Veterans' Family, Caregiver and Survivor

Federal Advisory Committee Minutes

September 23, 2021

1:00 PM – 1:05 PM Opening of the Federal Advisory Committee, Dr. Betty Moseley Brown

Dr. Betty Moseley Brown, the Designated Federal Officer, opened the meeting and discussed the rules for this meeting.

Betty asked that if committee members are participating by phone, to please text their votes to her when the committee begins voting on the recommendations.

The public will be attending the meeting.

If there are logistical concerns, Betty asked that participants email veofaca@va.gov.

There was only one public comment submitted by Karen Bridge, and it was distributed to the committee prior to the meeting.

Betty announced that there was a quorum to carry on business and called on Senator Dole for her introductory remarks.

1:05 PM – 1:10PM Call to Order/Welcome, Senator Elizabeth Dole

Senator Elizabeth Dole brought the meeting to order and thanked the members and the public for joining. She acknowledged that much has changed since the last meeting and highlighted the recent events in Afghanistan as being particularly difficult for the military community. Senator Dole discussed the mental and emotional toll that the withdrawal had on veterans and their families, especially those who were concerned for the safety of Afghan allies in the region. She thanked veterans for their service, thanked military and veteran caregivers for their sacrifices, and honored surviving families who lost loved ones in Afghanistan. Lastly, she highlighted the 20th anniversary of the attacks on September 11th.

Senator Dole then stressed the importance of following CDC guidelines and receiving the vaccine in the effort to combat COVID-19.

Next, Senator Dole underscored that the goal of today's meeting is to achieve agreement on a set of recommendations significantly benefiting veteran families, caregivers, and survivors. These recommendations will be sent immediately to Secretary McDonough for approval.

Senator Dole thanked the staff at the VA, especially Dr. Betty Moseley Brown, for their work in organizing today's meeting. She also thanked her staff at the Elizabeth Dole Foundation for assisting the VA with this process. Lastly, she expressed what a privilege it is to serve with each committee member and thanked them for their dedication and eagerness to make positive changes in the lives of our three populations.

Senator Dole then welcomed the Chief Veterans Experience Officer, John Boerstler, to provide an update on how the VA is supporting families after the withdrawal from Afghanistan.

1:10 PM – 1:25 PM John Boerstler, Afghanistan Update

John Boerstler thanked the committee for inviting him to attend and mentioned that VEO values everything that the committee provides as leaders in this space. In response to the withdrawal from Afghanistan, VEO saw a 9% increase in calls to veteran centers and 5% increase in calls/texts to the Veteran Crisis Line. This increase has allowed veterans and families to communicate directly with the VA and receive support.

Additionally, Andi Martinez and Tim Hudek from VA launched a Ted Talk-style program that discussed how to address different issues, such as confronting stressors or transitioning from active duty to veteran status. These 15-minute episodes have a monthly viewership of two million.

John thanked the committee for their leadership and partnership during these turbulent months and looks forward to the discussion of recommendations.

Questions:

Sherman Gillums asked if 9-8-8 was being considered by VA and would be interested in hearing from Dr. Matt Miller on an action plan for this topic. John responded that 9-8-8 will go live next summer and that the VA is running suicide prevention campaigns. John explained that the VA has protocol set in place to identify veterans in crisis, including follow-up from the Veterans Crisis Line if a veteran shows signs of suicidal ideations in exit surveys following treatment. John concluded that Dr. Miller would be able to speak to the committee further on this topic.

Senator Dole thanked John for his participation.

1:25 PM – 1:40 PM Dr. Steven Lieberman, COVID-19 Updates

She then welcomed Dr. Steven Lieberman and invited him to present the VA's efforts to combat the COVID-19 pandemic.

Dr. Lieberman thanked the committee and affirmed that he values the voice of the committee and their efforts to provide veterans with the best healthcare.

Dr. Lieberman began by discussing the interim final rule that was published on September 22nd that expanded benefits to legacy individuals for an additional year. This extension was implemented to allow the VA to re-evaluate all of the families and make a judgement based on the criteria set on October 1, 2020 by the Final Rule. If veterans are found to be ineligible for PCAFC based on this criterion, they will be given a 60-day notice and a 90-day notice for benefits after October 1, 2022.

The VA recognizes that the pandemic has been incredibly difficult for caregivers and encourages families to go to www.caregiver.va.gov for resources. As for COVID-19, the VA was optimistic that the country was on the upswing, but acknowledged that vaccination rates stagnated as the

Delta Variant became more rampant. Many VA hospitals are not experiencing the same bed shortages as other hospitals around the country; however, the areas that are challenging the VA's capacity are similar to those in the private sector. In order to address this, the VA has surged its staffing and recruitment to help support their "Fourth Mission" and open their facilities to non-veterans. Even with this increase, the VA has never turned away care to a veteran over a non-veteran.

60% of veterans (approx. 11.4 million) have received at least one dose of Moderna, Pfizer, or Johnson & Johnson. Of this 60%, 3.2 million have received two doses. Due to the passage of the SAVE LIVES Act, the VA received authority to vaccinate caregivers, dependents, survivors, and veterans outside of VA care. 5,000 veterans, 7,000 caregivers in PCAFC, 18,500 additional caregivers, and 61,300 spouses have been vaccinated due to this legislation. The VA will also administer booster shots under this same authority and follow guidance from the FDA in this area.

Despite the challenges, VAMCs have remained open with safety measures in place to protect patients and staff. All staff must be fully vaccinated and anyone entering the facility are required to wear a mask and practice social distancing. The VA has also increased testing and has added extra precautions to protect vulnerable veterans. Dr. Lieberman emphasized that the VA treats all veterans, regardless of vaccination status. The VA is continuing to do in-person appointments as well as telehealth appointments to assist rural veterans. Every VA facility has a Digital Divide Consult, in which a social worker can assess the veteran's home environment and work with them to ensure that they are receiving effective treatment, especially if they choose to have virtual assessments.

Dr. Lieberman shifted to a discussion about veteran suicide prevention. The findings of the 2021 National Veteran Suicide Report used data from 2019, as there is often a delay in data due to the difficulty in accessing death records, determining cause of death, and verifying that the deceased was a veteran. In this report, the VA found that many veterans were found to have been suffering from a mental health condition or substance abuse. The VA's goal is to partner with local communities as well as the private sector to combat these issues. The report also showed signs of hope for this issue, as veteran suicide decreased by four times compared to the previous year. The report also showed a 13% decrease in suicide amongst female veterans. Despite these optimistic figures, military service still increases the risk of self-harm and suicide. Dr. Lieberman emphasized that families are anchors for veterans suffering from these challenges.

Anyone can call the VA Crisis Line at 1-800-273-8255. If the caller is a veteran, they can press one. The events in Afghanistan and the 20th anniversary of the September 11th attacks significantly increased the volume of calls regarding mental health concerns to the Veteran Crisis Line. These events also had profound effects on caregivers and families, and Dr. Lieberman credited them for their hard work managing this amidst a pandemic. To address this, the VA published a four-part series on VA Vantage to help those who are struggling. This can be found at blogs.va.gov/vantage.

Dr. Lieberman proceeded to outline the priorities of the Veterans Health Administration. First and foremost, the VA is using high-reliability organizations to ensure that all VA Medical Centers are as safe as possible. Additionally, they are working diligently to prevent errors and eliminate patient harm.

Second, VHA wants to ensure that all individuals feel comfortable when they visit VA facilities. Dr. Lieberman heard recently from women and the LGBTQ+ community that they are harassed by other veterans. VHA is working on educating and training staff to intervene during these incidents and explain that this behavior is unacceptable. They are also working towards diversifying the workforces and ensure equitable healthcare for all races, ethnicities, genders, and sexual orientations.

Finally, VHA is making substantial progress in the study of cancer cells and administering targeted therapies that leave healthy cells intact. They are also focused on preparing for the “Silver Tsunami,” in which the population of veterans ages 65 and older is increasingly growing. VHA wants to ensure that veterans have the option of remaining in their homes, and therefore caregiver programs need to be strengthened to support this need. Lastly, VHA is taking lessons learned from the pandemic to address staff and caregiver burnout.

Dr. Lieberman thanked caregivers, families, and survivors for their sacrifices and emphasized that their work does not go unnoticed.

Questions:

Alfie Alvarado Ramos asked if the committee will receive a briefing on the assessments for legacy individuals so they can better understand where applicants are failing in their inability to stay in PCAFC. Dr. Lieberman ensured that the VA will be using the same criteria that is used in the current enrollment process and will be more transparent.

Sherman Gillums noted that staff burnout has significantly impacted the VA, especially at the DC VA, in which staff passed away due to COVID-19. He asked about the mental wellbeing of the staff and what the VA has implemented to mitigate attrition. Dr. Lieberman acknowledged that staff were exhausted and that it was a major concern of his. In the recent weeks, the VA has lost more staff than earlier in the pandemic, especially staff that chose not to receive the vaccination. He stressed that the VA needed to do more to support their staff, including looking out for one another, giving staff routine breaks, and utilizing employee assistance and chaplain services. Dr. Lieberman acknowledged that this was a major challenge across the country.

Melissa Comeau asked Dr. Lieberman if the VA is looking at vaccinating children of veterans. He responded that the VA is vaccinating adolescents, but some staff are not comfortable with vaccinating children. Some staff have vaccinated those 12 and older but have not vaccinated anyone younger.

Mike Linnington mentioned the vaccine mandate for VA employees and asked if this would cause there to be a shortage in medical appointments for veterans. Dr. Lieberman said that despite some opposition, most employees are choosing to get vaccinated and does not expect a huge loss of employees because of this mandate.

1:40 PM – 1:45 PM Meg Kabat, VA Update

Senator Dole welcomed Meg Kabat, Senior Advisor to the Secretary for Families, Caregivers, and Survivors, to the committee.

Meg thanked the committee and sent regards from the Secretary, Deputy Secretary, and Chief of Staff. The VA's uptick in COVID-19 cases mirrors that of the rest of the country and they have been working with FEMA to assist hospitals that have been overwhelmed by the influx in patients. The VA also worked with DHS to host a vaccination clinic at the southern border and vaccinated 25 veterans who were deported.

In an effort to increase transparency, Secretary McDonough has started to host press conferences that are live streamed. This unprecedented change allows the public to see the secretary respond directly to questions once a month.

Senator Dole thanked Meg for presenting to the committee.

1:45 PM – 1:55 PM Break

1:55 PM – 2:20 PM Dr. Colleen Richardson, PCAFC Update

Senator Dole introduced VA's Caregiver Support Program Executive Director, Dr. Colleen Richardson, to provide an update on the expansion of the Program of Comprehensive Assistance for Family Caregivers and an update on reforms to the appeals process.

Dr. Richardson informed the committee that the Caregiver Support Program (CSP) at the VA Central Office has hired 28 full-time employees, for a total of 44 VA staff. They are still working on filling the remaining vacancies but hired the final key member of leadership last week.

The office has six workstreams: Data and Analytics, CARMA & EHRM, Policy and Regulations, Training and Education, Centralized Eligibility Review Teams, and Field Operations.

93% of field-based staff have been hired, with 1,870 new employees.

In anticipation of the increased volume in new applications for the PCAFC expected during Phase II of Expansion (to begin in October 2022), the VA has trained staff and is prepared for the influx. In addition to the review of new applications, CPS staff will also need to complete more than 13,000 reassessments.

In FY21, CSP received more than 107,000 applications. These new applications are being prioritized over the re-evaluation and reassessment of legacy participants. Despite a 350% increase in applications over the past year, CSP is working diligently to make fair, equitable, and timely decisions.

PCAFC Application Data in FY21:

- 81,200 applications denied
- 12,900 applications approved
- 15,100 applications in processing
- 107,000 applications total

Dr. Richardson credited the following factors that attributed to the high denial rate:

- Veteran does not have a Service-Connected Disability Rating of 70% (15% of applicants)
- Veterans' injury was not incurred on or after September 11, 2001, or on or before May 7, 1975 (13% of applicants)
- Veteran does not need personal care services for a minimum of six months based on an inability to perform an activity of daily living or a need for supervision, protection, or instruction (43% of applicants)
- Veteran or Family Caregiver applicant withdrew their application (22% of applicants)

In discussing the recent change made to legacy re-evaluations, Dr. Richardson defined Legacy Applicant and Legacy Participant. A Legacy Applicant is a veteran or service member who submitted a joint application for PCAFC before October 1, 2020 and for whom a Family Caregiver was approved and designated on or after October 1, 2020. A Legacy Participant is an eligible Veteran whose Family Caregiver was designated by VA as of the day before October 1, 2020.

On September 22nd, 2021, VA issued a new regulation that would extend benefits to all legacy individuals for an additional year while they continue to re-evaluate families based on criteria set by the Final Rule in October 1, 2020. If they are denied, all legacy individuals will continue to receive benefits until October 1, 2022, regardless of when in the year they receive a denial. In this process, CSP wants to ensure that they are consistent and standardized, regardless of which VA conducts the assessment. Dr. Richardson also wants to ensure that the evaluation is standard across all eras of service. The office is working to complete 18,000 re-assessments over the next six months.

The veterans going through re-assessment will be impacted in one of three ways:

1. If they are determined to no longer be eligible for PCAFC, they will be notified after October 1, 2022, and the decision will take effect no less than 60 days from the VA issuing the notice. Family Caregivers will receive an additional 90 days of extended benefits.
2. If they are determined eligible, but at a lower stipend amount, they will be notified after October 1, 2022, and the stipend change will take effect no less than 60 days from the VA issuing the notice.
3. If they are determined eligible, but at a higher stipend amount, they will be notified and the stipend change will take place immediately.

Dr. Richardson also provided an update on the Program of General Caregiver Support Services (PGCSS). PGCSS provides resources, education, and support to caregivers of veterans from all eras. The program offers respite, mentorship, information, and caregivers can apply at any time, even if enrolled in PCAFC. PGCSS consists of four elements: Education and Support, Collaboration and Partnership, Resources and Referrals, and Outreach. The program office has hosted annual caregiver summits, resource fairs for caregivers and their families, caregivers listening sessions, partnership showcases, and has partnered with the Elizabeth Dole Foundation to provide no-cost respite to caregivers.

Finally, Dr. Richardson briefed the committee on VA Caregiver Support Line (CSL) updates. Over the past year, CSL has received over 130,000 calls. This is a 102.8% increase in call volume from FY20. About 19% of the calls resulted in a referral to a Caregiver Support Coordinator. Additionally, the office responded to approximately 1,700 email inquiries. CSL

also offers education groups every month on various topics, including empowerment, stress management, setting boundaries, and financial wellness. During the withdrawal from Afghanistan, CSP made 1,200 phone calls to caregivers and their families to check in on their wellbeing. The staff mentioned that this was incredibly rewarding and that caregivers often noted that the call was unexpected, but greatly appreciated.

Questions:

Melissa Comeau asked that for the 2,500 veterans who passed away during the application process, was there any outreach or support for the surviving families? Dr. Richardson acknowledged that she did not have much information on this piece, but that VA should be partnering with Bonnie Carroll from TAPS to ease this transition.

Melissa also asked that for the 6,600 that were determined to not be in the best interest of the veteran, how many were cases of domestic violence. She also asked if applicants who were denied can appeal through the Board of Veteran Appeals (BVA). Dr. Richardson and her team partners with Dr. Brooks in the social work office to reach out to the family and best navigate this precarious situation. Both a veteran and caregiver have been cited as abusers in cases and have asked to be withdrawn from the program. As for BVA, CSP is working with the Office of General Counsel to assess the ramifications of the Beaudette case and move forward.

2:20 PM – 2:35 PM Bonnie Carroll, Caregiver to Survivor Briefing

Senator Dole introduced Bonnie Carroll to discuss the recent Caregiver to Survivor work being completed between TAPS, The Elizabeth Dole Foundation, and the Red Cross Military Veteran Caregiver Network (MVCN). Bonnie noted at the start that it was Gold Star Family remembrance week.

Bonnie stressed the impact and scope of this work, especially with regard to caregivers. In total, Bonnie expects 397,000 individuals to eventually be able to benefit from the work being done to better prepare caregivers to become survivors. To demonstrate the scope of this need, Bonnie presented the following statistics:

Military and Veteran Deaths (FY20):

- 592,682 veterans died
 - 8,582 in a VA Inpatient Hospice Bed
- 38,889 veterans enrolled in VA received a Palliative Care Consult
- 8,359 veterans enrolled in VA received a VA-paid Home Hospice
- 224,226 service members and veterans completed the Burn Pit Registry since 2014

Military and Veteran Survivors (FY21):

- 456,445 military and veteran survivors receive Dependency and Indemnity Compensation (DIC)
 - 96% are spouses
- 9,446 estimated new military and veteran survivors will connect with TAPS
- 6,263 new military and veteran survivors connected with TAPS since January 2021
- Reported causes of death:

- Illness (31%)
 - 67% reported requiring a caregiver
 - 57% reported death was cancer-related
- Suicide (30%)
- Combat (3%)

Bonnie then looked at the trends of the causes of death. Hostile, or combat-related, deaths peaked in 2009 and have steadily decreased. However, suicide and illness deaths have increased. There are now over 9,000 newly bereaved survivors.

Bonnie also thanked Steve Schwab of the Elizabeth Dole Foundation and Melissa Comeau and Koby Langley of the Red Cross MCVN. She discussed the comprehensive literature review with the Elizabeth Dole Center of Excellence. The Caregiver to Survivor initiative hosted four different informative focus groups that were formed from surviving families. The goal was to gain frontline experience from those who have undergone the transition from caregiver to survivor.

The next step in the process was to identify and organize a catalog of resources that survivors can use. It is paramount to get those resources into the hands of those who need them most. Bonnie stressed that the most important question to answer is “how are we following up with those who experience a loss?”

In researching the caregiver to survivor journey, studies found that most interventions to improve outcomes during the transition include a focus on specific aspects of bereavement, deploying resources during the right points, are narrowly defined, target individuals, and are contacted before the bereavement process. Research also found that caregivers may be exposed to chronic stress for years, even decades. Bereaved, or surviving caregivers are at greater risk for living with depression, have greater stress levels, and experience greater isolation.

Bonnie concluded by adding that the Elizabeth Dole Foundation’s Respite Relief program was found to be one of the most beneficial resources for military and veteran families. It is critical to continue validating the actions of seeking help and validate the importance of caregiving.

The full report of the research and focus group findings will be published in November.

Questions:

Senator Dole asked Bonnie whether there may be a major obstacle preventing the VA from taking on this challenge. Bonnie answered that the biggest obstacle is the inability to look at the entire family system. Existing data provides an incomplete picture and each veteran has a family support system that has been impacted in one way or another. Steve Schwab added that the work borne of this committee and the deliberations and strength that Senator Dole and other leaders have shown on this topic has brought this issue to the forefront. He also stressed the importance of recognizing where the gaps lie in the VA system.

Sherman Gillums noted that it’s becoming more difficult to cope with death, especially as illness becomes a leading cause. He asked Bonnie if there was anything that stood out to her in this unprecedented time. Bonnie answered that toxic exposure is something that needs to be monitored closely. Secretary McDonough recently announced more presumptions that would

allow veterans to receive compensation for their exposure. Bonnie added that warfare has evolved as more soldiers are surviving their wounds sustained in combat. She concluded that it is critical for the civilian community to acknowledge life in service.

2:35 PM – 3:55 PM Discussion of Recommendation

Survivor Subcommittee – Recommendations

Potential Recommendation 1: Increase Collaboration to Offer Evidence-based, Caregiver Survivor Peer Support for Grief and Bereavement

Given the increase in Veteran deaths from COVID-19, chronic illness from toxic exposure, and sudden loss from suicide, families and caregivers are increasingly struggling with the experience of grief and bereavement. Research and focus groups have shown that they need—and benefit from—the trusted, culturally sensitive, and skilled grief and bereavement support not only from trained clinicians but also from trusted peers.

The VA and its relevant programs can best help meet this increased need for caregiver survivor peer support in the near term by increasing its collaboration with, and referral to, established, evidence-based programs offering: grief and bereavement support; peer support training, matching, and supervision; care and benefits assistance navigation services; and/or 24/7 grief and bereavement helplines.

Vetted programs offering these services, especially from military, veteran, non-profit and faith-based organizations with existing relations with the Department and its relevant programs in the VBA Office of Survivor Assistance, the VHA Office of Hospice Care Service and the Center for Development and Civic Engagement, and the NCA Survivor Benefits Office, the Veterans Experience Office (MOAs) others, *should immediately* be engaged by the Department in an intentional coordinated effort to ensure that caregiver survivor family members—of all eras, all relations, all services, all causes of death—have access to these needed peer support services through the sharing of information, training and referrals to proven non-governmental programs, resources, and services.

Rationale: The loss of a military or veteran loved one, whether expected or sudden, and the subsequent transition from caregiver to survivor can be an overwhelming time of mourning that can immobilize entire families and have lasting impact on their health and welfare.

Having a trusted source of compassionate caring from someone with similar lived experience to offer understanding, informed guidance and motivational hope is critical to the transition journey. This is especially important for those experiencing the loss of a veteran loved one from suicide given the frequent challenges to care and benefits access and the complexity of the suicide postvention grief journey.

Understanding how to assess the care, benefits and memorial services needed and available is daunting and overwhelming. It is critical that these individuals have access to information and assistance from both public private and non-profit sector professional providers to access the

care and benefits and memorial assistance and as importantly from the essential understanding and mentoring of peer support in order to navigate the process.

Through the enhanced collaboration of existing VA and non-VA programs (especially those from Veteran, non-profit and faith-based organizations) the Department can: 1) keep the Secretary's commitment to the principles of service for Veterans families, caregivers and survivors published in the Code of Federal Regulations (38 CFR Part 0 Subpart A 0.603) 2) meet the goals of the Joining Forces initiative for collaboration between federal agencies and non-profit organizations to address the well-being of military and veteran families, caregivers and survivors; and 3) offer services without the unnecessary delay in the delivery of support, the diversion of dedicated personnel or the additional and unnecessary expense of committed appropriations.

Questions:

Bonnie Carroll suggested changing “vetted” to “verified” in the recommendation.

Lee Woodruff added that she believed this recommendation was important and was completely in support. Melissa Comeau added that it is critical to include anticipatory and ambiguous grief so that caregivers and survivors are continuously validated.

Jenna Dorn referred back to Bonnie's answer on what was impeding the VA in addressing this issue. In order to address this challenge, the VA needs to maximize partnerships with outside organizations.

Lee Woodruff added that it is critical for caregivers to prepare for incoming changes in their life and the sense of grieving the partner you dreamed of. She noted that caregivers feel that they do not deserve to grieve, because their partner is still alive. Bonnie added to this sentiment that caregivers often grieve over the life they had. Melissa Comeau mentioned that MVCN studied complex grief and developed peer support programs to address this issue. She also stressed the importance of utilizing the journey map and connecting with caregivers at pivotal points.

Potential Recommendation 2: Improve the Engagement of, and Outreach to, Caregiver Survivors of Toxic Exposure

The increase in the number of caregiver survivors— who have experienced the loss of a Veteran due to chronic illness associated with their military service, especially from toxic exposure— has enhanced challenges in the military community. Sending increased requests to Congress, VSOs and non-profit organizations are trying to fill the needs of caregiver survivors. It is also renewing the Department's attention to the thousands of Veteran loved ones struggling to access and navigate the care, benefits, and memorial services they need and are entitled to both before, and after, their loved one's death.

The Department should present a plan for how they intend to strategically address the needs of these caregiver survivors by their intentional engagement in: (1) the consideration of policy; (2) the delivery of relevant services; and (3) the evaluation of policy and programs. This plan should facilitate improvements to the experience with benefits, care, and memorial services across the

journeys of caregiver survivors. It should further be continuously updated, as this is an ever-evolving issue. This plan should be presented to the Federal Advisory Committee by March 2022.

Rationale: Given the increased knowledge on the clinical impact of toxic exposure on Veterans health and welfare, the growing number of Veterans diagnosed with chronic conditions that are associated with their military service, the challenging experiences of caregiver survivors – and their children and youth - who have cared for Veterans with toxic exposure, and increased Congressional attention to these Veterans and their families, it is critical for the Department to engage the caregiver survivor community in its development, execution and communication of a clear strategy that includes not only care and memorial services for the Veteran but care and benefits for their survivors. By involving caregiver survivors of toxic exposure in its efforts, the Department will help demonstrate its commitment to respect, understand and improve their experience.

Questions:

Denton Knapp noted that there has been great progress made with Agent Orange and has influenced the way the VA studies Burn Pits and depleted uranium for Operation Iraqi Freedom and Operation Enduring Freedom veterans. Bonnie Carroll added that the committee needed to ensure that the recommendation was using inclusive language.

Sherman Gillums added that he anticipates that COVID-19 will have compounding and lasting effects on those who already have chronic illnesses. Therefore, the recommendation should include COVID-19 and its complications.

Bob Koffman mentioned that cancer amongst veterans has increased by 1.5%. Bob asked that because of this, should the committee look at the crossover between toxic exposure regulations and cancer regulations? Bonnie answered that we could address this, but the committee would also need to know how the VA is currently informing these veterans. Bob concluded that he would think about more direct wording for this recommendation.

Recommendation 3: Increase, and Share, Verified Information on Caregiver Survivor Resource and Services

Veteran caregiver survivors have expressed their critical need for assistance in accessing, understanding, and successfully using the many sources of information on care, benefits, and memorial services that they need and are eligible for and are entitled to. Navigating the tens of thousands of public-private and non-profit sector sites, finding verified resources and services, and applying for their assistance is overwhelming— especially as they transition from their role as a caregiver to their role as a survivor.

The Department of Veterans Affairs— in collaboration with the Departments of Defense, Labor, Health and Human Service, other agencies and Military, Veteran, non-profit, and faith-based organizations— *should* enhance all its multichannel sources and content to ensure that the information it offers through public sources is consistent with its commitment to serve and support this important population.

These enhancements should utilize CX principles and practices consistent with the VA commitment to customer experience. They should specifically involve the voice of the Veteran caregiver and survivor community and the relevant external stakeholders that help serve them.

Products from this effort *should* include, but not be limited to:

1. The publication and multichannel presentation of a comprehensive, easy-to-use guide for survivors that outlines existing resources and services for Veteran families, caregivers and survivors. The existing [VA Survivors and Burial Benefits Kit](#) should be revised so that it is clearer, more understandable and easier to use (e.g. technical terms should all be defined and processes and programs explained).
2. The dissemination of information on, and access to this enhanced information should be done in a concerted effort to communicate most effectively with a wide range of stakeholders serving Veterans and their families, caregivers and survivors (e.g., educational institutions and employers, state and local agencies, funeral home directors, coroners' offices, military/veteran/non-profit and faith-based organizations, etc.) in order to enhance their understanding of the experience of Veteran survivors and the referral to VA's survivor care, benefits and memorial services.
3. The identification of existing vetted resources and services that support military and veteran caregivers throughout their survivor journey should be undertaken starting with the examination of existing information sources such as the National Resource Directory (NRD), the Hero Care Resources (Aunt Bertha) and PatriotLINK and others. Gaps in resources and services should be identified and information collected and incorporated where available. When needed, new resources and service needs should be considered in collaboration with external stakeholders to increase responsiveness, expand reach and reduce redundancy.

VA should complete this recommendation by September 2022 and make these resources available to the public.

Rationale: Grief is a long and complex journey. From prognosis to years after a loved one is gone, there are multiple opportunities to provide a bereaved, or soon-to-be bereaved, family and caregivers with helpful and preparatory resources. Many current VA resources are still difficult to access and understand and their use and benefit could be increased with user input. For example, attractive template of the [VA Survivor Quick Start Guide](#) means that a number of terms are left undefined and thus limit its utility.

All information, resources and guides should be reviewed, developed and published (hard copy and/or electronically) in ways that are demonstrated to help surviving family members navigate the myriad of care, benefits and memorial services available to them. By offering more clear, understandable and usable information to caregivers and survivors, and the providers and peers who assist them, across their journey they will be more able to anticipate and plan for the most likely moments that matter (e.g. legal and financial requirements) rather than to be introduced to the complex process of care, benefits and memorial services access during their time of grief.

Questions:

Bonnie Carroll suggested changing “vetted” to “verified” in the recommendation.

Senator Dole commented that the subcommittee did an excellent job in formulating the recommendations and noted that resources that are easier to use and more accessible to families have been a popular theme throughout the committee. She asked Gabby Kubiyni to comment on the role that employers play in terms of this journey. Gabby responded that it is critical that employers know what resources exist within this space. She added that many spouses are unaware that their income will sharply decrease once their veteran passes away. Because of this, it is important to make the information more available and allow families to start this conversation earlier in life.

Alfie Alvarado-Ramos commented that she valued the ability to comment on this issue and that the VA needs more examples of salient issues.

Melissa Comeau added that the Caregiver to Survivor group looked at this issue and found that the tens of thousands of resources available can overwhelm a grieving family. To address this, the group looked at their journey map to identify key moments in which a few verified resources were more impactful.

Denton Knapp noted that many families rely on the American Legion, Veterans of Foreign Wars, and other Veteran Service Organizations for assistance. He emphasized the importance of the VA consistently updating these offices.

John Boerstler concluded that when this recommendation is approved, VEO will structure this resource similarly to the VA Welcome Kit, which is the most downloaded resource they offer. He also stressed that they will work to make it more consumer-centric.

Families & Caregiver Subcommittee – Recommendations

Recommendation 1: The Department should conduct a formal, quantitative survey that analyzes the current veteran population to understand gaps and challenges that may exist for families with children. This survey should be completed by June 2022.

Rationale: As we learn more about the caregiving community it has become abundantly clear that children have been left out of this demographic, despite the enormous impact that it has on their lives. Issuing a survey of this population will help the Department better understand their needs and create resources to assist them where necessary. Additionally, this is an investment in our country’s readiness as 30% of military children end up enlisting in the military.

Questions:

Senator Dole asked Kate Shattuck how the events in Afghanistan have impacted her family, especially her children. Kate emphasized that her six children are all helping their father grieve. Two of them are in the service, and Kate would not be surprised if her youngest enlisted one day. Kate mentioned that her ten-year-old is her husband’s caregiver by comforting him when necessary. Over the past month, the Afghanistan War has been front and center in the minds of her family and emphasized that this conflict impacts the entire family, not just the service member. Kate concluded that she resonates with this recommendation and hopes that the VA seriously considers this issue.

Sherman Gillums added that his daughter is also in the Armed Services and was surprised at her decision to enlist. He suggested that the VA should consider including veterans who are children of veterans to understand the impact that growing up in a military family has on children and their choice to enlist. Sherman also noted that surveying children might be difficult, so the VA should ensure that they are sensitive in their approach. Steve clarified that it is up to the Veterans Experience Office (VEO) to decide how to execute this recommendation, especially since the VA does not have programs that specifically support children. Ideally, the VA should be holistic and include the entire family, but there is not an ideal avenue to outreach to this population and data on their needs is scarce. Lee Woodruff added that capturing information on this population would be helpful for external organizations and non-profits that support the needs of children. John Boerstler concluded that the Office of General Counsel might limit VEO's authority in this aspect, but they can find other ways to support this population. For example, the Elizabeth Dole Center of Excellence is conducting research on children ages 12-18 who are serving as primary and secondary caregivers to their parents. John added that this may be difficult given that children are not direct beneficiaries of VA services. Steve Schwab added that the same was said about caregivers 10-15 years ago but the VA was eventually able to overcome this technicality.

Recommendation 2: The Department should present a plan for how it intends to regularly outreach and explain criteria to potential applicants to the Program of Comprehensive Assistance for Family Caregivers. The VA should develop material to send to those who have been denied from the program that includes information on the Program of General Caregiver Support Services (PGCSS), the Respite Relief Program, and any other resources that are available. Additionally, the application for PGCSS should be concurrent with the application for PCAFC and allow family members to apply for both programs simultaneously.

Rationale: By overseeing the process to be admitted into PCAFC, the VA has access to a large group of caregiving families who are in need of assistance. When the VA issues a denial, they have an opportunity to cushion the decision and provide resources to these families. This would acknowledge that they are caregivers and have other options for assistance. By standardizing these materials, it would also aid external groups in their efforts to help families denied from the program.

There were no questions or remarks on this recommendation.

Recommendation 3: The Department should establish a policy that clearly articulates that families enrolled in VA programs will not face retribution or lose their group status if they accept financial support from other government programs groups (e.g., SNAP benefits).

Rationale: In anticipation of the return to a post-pandemic world, it is critical to address the financial impact that the pandemic had on military and veteran families. Even though it would help their family greatly, many are hesitant to utilize government aid in fear that it will impact their status in VA programs or cost them more in the end. With job loss and food insecurity impacting a significant portion of the military and veteran community, it is critical that the Department's policies are not adding unintended consequences to those seeking financial aid from other agencies.

Questions:

Meg Kabat asked if the committee could clarify this recommendation, as there are currently no income requirements for VA programs. Steve Schwab noted that the subcommittee discussed that there was a perception that families would lose VA benefits if they utilized other financial programs within the government. Meg responded that there are rules around disability compensation, but the VA could be more clear on how the VA's monetary benefits and services interact with those of other agencies. Lee Woodruff added that consumer-friendly materials that explain these benefits could be added. Meg mentioned that VEO helps veterans and their families apply for SNAP benefits and take a whole government approach to addressing these issues.

Alfie Alverado-Ramos asked if the stipend for the Program of Comprehensive Assistance for Family Caregivers was considered income. Meg replied that it is complicated, as it is not considered income for the purposes of federal taxes. Alfie clarified that she was concerned that it might be considered income for the purposes of SNAP and that the individual would be penalized and unable to access both programs.

Gabby Kubiyni asked how the VA interacted with Medicare and Medicaid. Meg stated that it would be advantageous to clarify this point, as more aging veterans who use these programs are qualifying for PCAFC. She added that this should be addressed with a quick-start guide, to which John Boerstler mentioned that there are guides in place for this issue. Meg concluded that it would be beneficial for the VA to explain how their benefits interact with other federal programs.

Recommendation 4: Due to new thresholds set by [SAVE LIVES Act](#), the Department should establish a national registry for caregivers in order to track participants and their activity in PCAFC, PGCSS, and CHAMPVA in the next fiscal year.

Rationale: The SAVE LIVES Act (P.L. 117-4) gave the Department of Veterans Affairs the authority to vaccinate caregivers in PCAFC, PGCSS, CHAMPVA beneficiaries, spouses, and veterans outside of the VA health system. This legislation offers the Department a unique opportunity to learn more about the caregiver population and contact them directly. Using this law as precedent, other benefits may be distributed to this group in a similar manner. By creating a national registry for caregivers, the Department and external stakeholders can disseminate important information more effectively, better understand their needs, and reduce the stigma associated with caregiving.

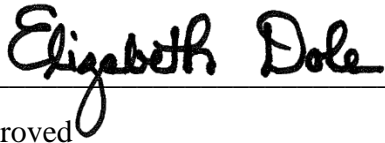
Lee Woodruff added that this would be useful in outreach and the dissemination of information to this group. There were no questions on this recommendation.

Lee provided an update that she and Dr. Bob Koffman have been studying holistic alternatives for treatment. The Family and Caregivers Subcommittee were briefed by Dr. Rachel Yehuda on the efficacy of psychedelics on treating bereavement, PTSD, and other conditions. This is an issue that they are looking at addressing in the next Federal Advisory Committee meeting.

Concluding the discussion of the recommendations, Senator Dole conducted a vote on the recommendations. All seven recommendations passed unanimously and will be sent immediately to Secretary McDonough.

3:55 PM – 4:00 PM Wrap-Up & Adjourn

Senator Dole thanked the committee members for their outstanding participation and adjourned the meeting.

A handwritten signature in black ink that reads "Elizabeth Dole". The signature is written in a cursive style with a large, prominent "E" and "D".

Approved

Senator Elizabeth Dole, Chair

Approved

Betty Moseley Brown, Ed.D.

Committee Members Present:

Sen. Elizabeth Dole, Committee Chair

Sherman Gillums, Jr., Vice Chair

Lourdes E. “Alfie” Alvarado-Ramos

Bonnie Carroll

Paula Cobb

Melissa Comeau

S. Joe Crittenden

Jennifer “Jenna” Dorn

Mona Gunn

Everett “Denton” Knapp

Dr. Robert L. Koffman

Gabriella Kubinyi

LTG Michael S. Linnington, (USA Retired)

Dr. Rebecca Porter

Kate Shattuck

Sarah Verardo

Lee Woodruff

Committee Members Excused:

Hollyanne Milley

Harriet Dominique

Department of Veterans Affairs Staff Present:

John Boerstler, Chief Veterans Experience Officer (VEO)

Steven Lieberman, Acting UnderSecretary for Health (VHA)

Dr. Betty Moseley Brown, Designated Federal Officer (DFO)

Janet Elder, VEO Management Analyst

Margaret Kabat, Sr Advisor to the SECVA for Families, Caregivers and Survivors

Dr. Luci Leykum

Jeffrey Moragne

Helene Moriarty, VHA

Dr. Colleen M. Richardson, Executive Director, CSP

Lenicia Smith

Krystal Toles

Public Present: (Note: the meeting was virtual, open to the public, attendance could not be taken or confirmed.)

Bailey Bishop, Elizabeth Dole Foundation

Meredith Burns

Rene Campos, MOAA

Bob Carey, The Independence Fund

Holly Ferrell, Veteran Warriors

Brandon Hofacker, Elizabeth Dole Foundation

Dongmin Lee

Major Skye Martin, USMC, Defense Information School

Larisa Owen

Rashi Romanoff, Elizabeth Dole Foundation

Andrea Sawyer, Wounded Veteran Family Care

Colleen Schillmaier, ERPi

Steve Schwab, CEO, Elizabeth Dole Foundation

Sam Solley, Revelations

Leah Thomas

Jennifer Tullis, TAPS

Olivia Valdez, Elizabeth Dole Foundation

Maggie Walsh, ERPi

Pat Williams

